

REDUCING HIV RISK BEHAVIORS AMONG KEY POPULATIONS BY INCREASING COMMUNITY INVOLVEMENT AND BUILDING SOCIAL CAPITAL: BASELINE FINDINGS FROM ANDRA PRADESH, INDIA

At the end of 2003, there were an estimated 5.1 million HIV-infected individuals in India, the second highest national figure after South Africa (UNAIDS 2004; NACO 2004). India, however, remains a low prevalence country with overall HIV prevalence of 0.91 percent among the adult population, compared to 21.5 percent in South Africa (NACO 2005).

In order to have the greatest impact on the epidemic in low-prevalence countries, there is growing recognition of the importance of focusing prevention efforts on people living with HIV and those populations most likely to be infected, such as sex workers and men who have sex with men (Ainsworth and Overs 1999). These populations are key because they are particularly vulnerable to being infected and to transmitting the virus, and therefore without their mobilization and empowerment, the epidemic will continue to grow (Global HIV Prevention Working Group 2003; Campbell and Mzaidume 2001).

This research update describes baseline findings from a qualitative study in India, conducted as part of a larger research and intervention project entitled the Frontiers Prevention Project (FPP). Managed by the International HIV/AIDS Alliance, with funding from the Bill and Melinda Gates Foundation, the FPP supports the delivery of a comprehensive package of interventions within specific geographic sites in India, Ecuador, and Cambodia that are potential high HIV-transmission areas. The FPP aims to reduce HIV incidence in these sites by reducing risk behavior and STI prevalence among three key populations—female sex workers, men who have sex with men, and people living with HIV.



INTERNATIONAL HIV/AIDS ALLIANCE

Training for members of key populations in Andra Pradesh.

The central hypothesis underpinning the FPP is that providing a comprehensive package of services and interventions to key populations will empower them to reduce risk behaviors. This will not only reduce transmission within each group but will also slow the spread of HIV more widely in the population as a whole. In order for empowerment for prevention to occur among key populations, it is necessary to improve their access to services, create an enabling environment free of stigma and discrimination, and build their social capital. In this study, social capital includes civic participation in groups and associations; and trust, solidarity, and reciprocal support within and across key populations and other groups.

The aim of this nested study in India, which was conducted by the Horizons Program and the Institute of Health Systems, was to explore issues of social capital, stigma and discrimination, HIV knowledge and behaviors, self-esteem, and service delivery among the three key populations in order provide information for the development and evaluation of the FPP.

Methods

This qualitative study was conducted in 8 out of 40 FPP sites in Andhra Pradesh, a state with one of the highest concentrations of people living with HIV in India. A total of 118 in-depth interviews were conducted across the 8 sites: 32 with female sex workers, 32 with men who have sex with men, 16 with people living with HIV, 24 with gatekeepers who interact with key populations, and 14 with NGO staff working in the sites. In addition to the interviews, 32 focus group discussions (FGDs) across the 8 sites were conducted—16 FGDs with female sex workers and 16 FGDs with men who have sex with men. Interviews were transcribed, translated, and entered into Atlasti.

Respondent Characteristics

The female sex workers who participated in the in-depth interviews ranged in age from 18 to 40. The majority were between the ages of 20 and 30, illiterate, married, and were street-based sex workers.

The men who have sex with men were between the ages of 18 and 52; most were under the age of 30 and were literate. A significant number of the men (26 out of 32) were sex workers. The majority of respondents over age 30 were married, while most who were younger were unmarried. Most respondents identified themselves as *kothis* or “not men”—namely men who are sexually penetrated by their male partners (referred to as *panthis* or “real men”). About half of the *kothis* exhibited feminine characteristics and some of them self-identified as transgendered.

The people living with HIV (10 female, 6 male) who were interviewed were between the ages of 18 and 48. A little more than half were married (9 out of 16) and half were illiterate. Among the females living with HIV, six were sex workers and four were housewives. Three housewives said their husbands had infected them, and the fourth blamed a blood transfusion for her infection. All six males revealed that they were clients of sex workers.

Key Findings

Families provide the most support to key population groups, who tend to distrust peers and the larger community.

Respondents were asked about the extent to which they felt supported by their families, their peers, members of their caste, and the larger community. Although low levels of trust and support were reported in general, all key population groups reported the highest levels of trust and involvement with their family members, including parents, siblings, spouses, regular sexual partners, and children.

I trust my parents and brothers as they look after me well. They take me to the hospital when I fall sick.

Female sex worker

I trust my wife and children. They are blood relations so I can trust them; if I feel pain they also feel something. With other males we can do friendship but we cannot trust them because they trust their family members but not me.

Male who has sex with men

Although peers were sometimes mentioned as a source of support, there was often mistrust of the wider peer community. Differences in age, status, and physical appearance led to jealousies and competition for clients and partners among female sex workers and men who have sex with men.

I don't trust anyone [sex workers]. No one can be trusted. People do a lot of backbiting.

Female sex worker

[I do not trust peers]. If one man is introduced to a male partner, then he will get a doubt whether someone might take away his partner tomorrow. Thus that friendship will not last long. They also feel that their secrets may be revealed outside and thus do not cooperate with each other.

Male who has sex with men

Key population group members also had a high level of mistrust of many of the people with whom they regularly interacted, such as neighbors and clients. However, a few female sex workers reported some trust and influence with regular clients who provided material and other support in times of need.

I trust them [two regular clients] because if I am running short of rice, I can go to them and beg. When I fall sick they will take me to the hospital.

Female sex worker

Overall, most members of key populations did not report any kind of support from their caste members, even though caste-based relations is a dominant aspect of the Indian socio-cultural milieu. Some lower castes in Andhra Pradesh have been associated with sex work either traditionally or because a large number of women belonging to the caste have turned to sex work in the face of poverty. Some female sex workers belonging to such castes reported that there was comparatively better acceptance of their profession within the community. A few had a voice in their community and could enlist support from caste members to prevent violence and abuse.

Many respondents are wary of participating in peer groups.

Though men who have sex with men tended to be more involved in peer groups, these groups were reported to lack cohesiveness despite being well-structured with specific roles for each member. Female sex workers had a comparatively lower level of involvement in peer groups, which were usually small informal groupings of sex workers working in an area.

While the identities of some street-based sex workers and the more feminized men who have sex with men were known to their communities, a significant number of respondents did not want to associate themselves with key population groups publicly and risk revealing their identities. Similarly, people living with HIV did not usually form groups, as they did not want their status known to anyone outside their immediate families and NGO staff.

Members of key population groups have mixed feelings about the services NGOs offer.

Most respondents reported having some involvement with local NGOs. They were willing to disclose their identity to NGO staff and especially to outreach workers. Outreach workers were generally seen as people who “listened to them,” whom they could approach in times of need. In particular, they were people who provided emotional support and access to medical care to people living with HIV.

NGO activities identified by respondents included peer education, provision of STI and condom services, and facilitation of access to HIV testing services and general health services. Involvement of key population groups in NGOs was mostly as recipients of sexual health services. Although there was general agreement that such services were beneficial, involvement of key populations arose out of the need for and expectation of support in a number of areas related to livelihoods and prevention of abuse. These include provision of vocational training and jobs; financial support to start a business; provision of identity cards, legal services, and safe spaces; and awareness and advocacy programs to tackle stigma and discrimination from the general public.

The few who were actively involved with NGOs expressed a sense of purpose and happiness in being able to contribute to their respective communities. However many respondents reported that they did not get any support from NGOs, resulting in distrust, disillusionment, and resentment.

Respondents from all groups have limited trust and influence in formal institutions.

Relationships with formal institutions, such as the police, social and health services, and political organizations, were generally characterized by a lack of support and by stigmatization and discrimination. Female sex workers in particular reported very low access to the social support services available to others in the community. Many of them were the sole providers for their families and as a result were required to interact with government staff involved in provision of ration cards, loans, civic amenities, and welfare services. Some sex workers reported that they were discriminated against, abused, asked to pay bribes, or denied redress of grievances at government offices. Despite such experiences, many respondents still looked to the government to improve the quality of their lives.

Some female sex workers were involved in political organizations, which sought their help to mobilize votes from their communities in exchange for food and money. However, the women had very limited influence within these organizations and reported that political organizations did not keep their promises after elections.

Family members are major sources of stigma, discrimination, and violence.

Among the female sex workers interviewed, their husbands, regular partners, or “temporary husbands” were normally aware of the respondent’s occupation and, in many cases, worked as gatekeepers to broker clients. In some cases, husbands deserted their wives once they came to know that the women were engaged in sex work. Respondents reported that they experienced degrading comments about their choice of work, physical abuse by husbands/partners, coercion by husbands/partners to part with their earnings, and forceful abortion when husbands suspected that a child was not theirs.

My husband married twice. My husband is an alcoholic and doesn’t take care of the house. He lives with the other woman. He beats me also. I am not educated. I can’t get a job and to feed my daughter I am doing this work.

Female sex worker

Stigma and discrimination experienced by female sex workers from family and relatives included derogatory comments, criticism and ridicule, abandonment, expulsion from the parental or marital home, not being visited or welcomed, not being invited to family functions, and being refused help or support in times of need.

Many of the men who have sex with men interviewed were married with children. Although some of their wives were aware that their husbands had sex with other men, most were not. Regardless of marital status, many of the men had regular male sexual partners, sometimes more than one.

Stigma and discrimination experienced by men who have sex with men from their families and relatives included degrading comments and ridicule pertaining to their sexuality, avoidance and isolation at social functions, denial of support, and desertion by wives.

People living with HIV reported similar experiences: abandonment by parents and siblings, desertion by spouses, derogatory comments from family members, and avoidance and isolation from social functions once their HIV status was revealed to family members.

Respondents also face stigma, discrimination, and violence from the community, including health care workers, the police, and clients.

Within the larger community, sex workers are highly stigmatized. Men who are engaged in sex work are doubly stigmatized on account of their occupation. Female sex workers reported comparatively more stigma from the women in the community who see them as a threat to their families, while men who have sex with men face comparatively more stigmatizing behavior from men in the community. Respondents from both groups reported that community members assign criminal attributes to them; they are seen as people who will do anything for money and petty thefts and robbery are frequently attributed to them.

Most respondents did not reveal their occupations or sexual identities when seeking health care from either government or private hospitals. When their identities were revealed while seeking medical care, respondents reported experiences of stigma and discrimination. A few respondents also reported discriminatory behavior from staff of NGOs engaged in HIV prevention work. Men reported that they were degraded and abused, that their identities were revealed to others in the community, and that they were denied services and expelled from health care facilities by doctors and hospital staff. Female sex workers reported that they were degraded and criticized, not examined properly, forced to undergo HIV tests, overcharged for services at private hospitals, denied medical services and delivery care, and that their identities were revealed to others in the community.

Some of the doctors, when we approach them for treatment, if they know that we are [kothis] they don't touch us and go away from us, ordering the [security staff] to send us out.

Male who has sex with men

Without conducting blood test and HIV test doctors do not touch us in hospitals. During delivery time when we want to have hospital delivery they do not admit us in hospitals for delivery.

Female sex worker

NGO staff and gatekeepers in the sites corroborated such experiences of discrimination. They revealed that, in some cases, doctors appointed by NGOs specifically for the purpose of providing treatment to female sex workers and men who have sex with men discriminated against them.

A significant number of respondents from both groups (female sex workers and men who have sex with men) reported discrimination and violence at the hands of the police. Female sex workers reported that they were verbally abused, beaten up, forced to have sex without payment, robbed of their money and other valuables, and threatened and harassed by the police. At times, they were arrested and fined when they were caught with a client. Sometimes, false cases were attributed to them when the police did not have enough cases registered at the police station.

Police people harass us a lot. They beat us very often and keep us in jail.... They come to our houses also and without even inquiring they start beating us.

Female sex worker

An overwhelming majority of male and female sex workers reported that they were stigmatized and subjected to violence by clients. They were beaten up, forced to have sex with multiple clients, robbed of their money and valuables, raped, coerced to have sex without condom or payment, forced to have “unnatural sex,” and abused and harassed by clients. Some of the men reported that clients sometime threatened to reveal their identities to their families and blackmailed them.

Clients hit [kothis] saying that we should do well as we are taking money. They pull our hair. Some times they don't give money.

Male who has sex with men

Respondents find it difficult to cope with stigma, discrimination, and violence, and are wary of seeking support from others, including peer groups and NGOs.

The majority of respondents who were female sex workers or men who have sex with men said that they felt “sad,” “bad,” “upset,” “scared,” or “ashamed” when faced with stigma and discrimination. Some reported that they felt “angry,” “depressed,” or “helpless.” A few felt suicidal or attempted suicide, and some said that they felt like giving up sex work.

I feel sad at the discrimination. Sometimes I wonder why I had to do sex work and I feel like dying.

Female sex worker

When my neighbors spoke ill of me, I felt very bad and consumed pesticide. I had to spend around 10,000 rupees to get treatment and gain consciousness.

Male who has sex with men

Coping strategies identified by the respondents included leaving a place when faced with abuse, avoiding perpetrators or situations where there was the possibility of getting stigmatized and abused, and not going out alone or going out with peers. A significant number of the respondents said that they retaliated when faced with stigmatizing behavior and abuse from the community. Indulgence in alcohol was a commonly adopted coping mechanism, especially by female sex workers.

Sometimes when people stigmatize us we will resign everything to God and ignore them thinking that they will only bear the consequences later. Sometimes I get crazy thoughts. I think that my life has become spoilt and that my children will also be spoilt. I become depressed then and go to the movies or consume brandy.

Female sex worker

A few respondents tried to cope with stigma and discrimination by sharing their experiences with parents, spouses or partners, friends, and peers. But, many felt that they have no one to turn to.

How can we go and tell people that we are prostitutes and these are the problems we are facing and so help us? They do not help us even if we say we are doing this work as there is no other way for us. In case we face any problems then we suppress it within ourselves but we don't go to anyone for help. If there is someone who can work for us then we can go to him or her for help. Many of our people are not ready to come forward because they know that their problems cannot be solved.

Female sex worker

For some, involvement in peer groups was seen as a coping strategy. Men who have sex with men in particular expressed a “feeling of belonging” in peer groups. Many were able to share their grievances with each other, and at times help each other. Some of them expressed the need for formation of stronger peer groups for better support. As described earlier, however, relations between peers are not always easy and because of a lack of trust, these groups can become unstable and disintegrate.

NGOs were also seen as a potential source of support, especially regarding prevention of abuse and violence, provision of alternate employment, and financial and material support. However, most respondents

reported that they did not get any such support. Neither did they have much voice or a decision-making role in the implementation of programs.

The NGO supplies only condoms. They do not provide any help during violence. We can buy condoms outside for one rupee, which we can afford. We need help to combat our problems. We can get rid of all these problems if the NGO can provide an alternative employment.

Female sex worker

Respondents have low levels of self-esteem due to a lack of capacities, self-confidence, and self-worth.

The self-esteem of respondents was explored by asking about three sub-themes: capacities (life and negotiating skills), self-confidence, and self-worth. Very few respondents reported having had the opportunity to develop any kind of life skills. Almost all the female sex workers and people living with HIV interviewed, and most of the men who have sex with men, came from a poor socioeconomic background. At least half of the people living with HIV and the female sex workers were illiterate. Lack of job opportunities, insufficient income from available work, lack of support from family and others, and the burden of supporting themselves and/or their families were the major reasons stated by respondents for their involvement in sex work.

Most respondents in all the groups expressed a number of fears that consumed their daily life and impacted their self-confidence. Many were apprehensive of their identities being revealed to family members and others. Female sex workers and people living with HIV were particularly concerned about the future of their children, especially daughters who were to be married. Fear of abuse and violence was inherent in the daily lives of men who have sex with men and female sex workers, as was the fear of contracting HIV and other STIs and accidentally infecting their spouses or partners. A significant number of respondents were worried about how they would pay back their debts and who would take care of them during their old age. A key fear expressed by many men who have sex with men was desertion by their partner.

Across the key population groups there was a high level of internalization of stigma. Many respondents felt ashamed because they were “doing wrong,” “sex work is “bad,” or sex between men is “unnatural” or “abnormal.” Men who have sex with men were particularly ashamed of being in the sex trade. Low self-worth on account of feelings of inferiority was seen across all groups. In general, poverty, lack of education, and stigma and discrimination were seen to be at the root of feelings of inferiority. Perceived poor physical appearance, low earning potential, street-based sex work, and low caste were also associated with feelings of inferiority among female sex worker respondents.

Utilization of health services by key population groups depends on a combination of factors, including accessibility and attitudes of providers.

General medical services and STI treatment and HIV testing services were sought from a mix of public, private, and NGO providers. Some sought STI and other treatment from traditional healers and other practitioners without formal qualifications. In some cases NGOs had their own clinics and directly provided medical and STI services. In other cases NGOs linked with local providers and clients were

brought to them by outreach workers. For HIV testing, NGOs generally linked with local public facilities such as VCT centers, which provided referral services.

According to respondents, their utilization of health services depended on a combination of factors, including location, responsiveness of staff, perceived quality of services, confidentiality, cost of services, and availability of a female doctor (in the case of female sex workers). Generally, respondents reported that government hospitals and NGOs were more accessible financially. However, many preferred other providers on account of the rudeness and non-responsiveness of staff, lack of confidentiality, discrimination, fixed timings, lack of doctors, and unavailability of drugs and diagnostics at government hospitals. Some people living with HIV also reported that they were not treated at government hospitals.

They are very rude with us. They don't keep secrets with them. They tell everybody about it. So it is bad for us. It happened to me when I went to the government hospital to get an operation. If we know somebody there then it is ok but if we don't know anyone they are very rude. I am scared to go to the government hospital.

Female sex worker

Some respondents reported that they preferred private health care institutions, alternate medical practitioners, and Rural Medical Practitioners (RMPs) who have no formal qualifications because they were more responsive and accessible than other providers. Many of the female sex workers sought treatment from “family doctors” who were usually RMPs. They were able to share their symptoms with such practitioners, and were assured confidential, prompt, and responsive treatment.

The majority of men who have sex with men and people living with HIV interviewed who reported being treated for an STI had consulted a medical doctor. Female sex workers, on the other hand, relied more on self treatment measures such as buying medicines directly from a medical shop, consumption of so called “cold foods” like buttermilk, or using dettol after sex. In some instances they were treated by traditional healers.

While private practitioners and small clinics were accessible for treatment of minor ailments, private providers often were not an affordable option for treatment of major illnesses, HIV-related conditions, and HIV testing. Since local government hospitals generally do not treat HIV patients, people living with HIV were at times forced to seek treatment from private providers. People living with HIV interviewed reported that the cost of treatment was very high, forcing some to discontinue it.

Condom use is inconsistent among female sex workers and men who have sex with men.

Generally, respondents from all groups shared the opinion that condoms were the best preventative measure against HIV, however this was not translated into practice, as overall usage was inconsistent. Female sex workers and men who have sex with men reported selective use of condoms, using them with some partners but not with lovers, husbands, or boyfriends. Reasons for not using condoms included non-consensual sex, liking and trusting certain clients/partners, and confidence in one's own negative HIV status.

Some respondents spoke about insisting on condom use with clients; this insistence consisted of explaining, negotiating, and demonstrating to clients the use of condoms. If the client refused to use a condom, some spoke about pushing away the client even if it meant a loss of income.

Sometimes we don't use them [condoms]. If there are some good people they might use the condom. If they are drunk, they ask us what disease they have and start hitting us. If we tell him to wear he wears. If he does not like it, he beats us up.

Male who has sex with men

I don't use condoms with everyone. Some of them would not bring them. In case they don't bring it we will have sex without condom.

Female sex worker

Respondents from all groups received condoms from NGOs engaged in HIV prevention work, mostly through outreach workers. Condoms were also provided in safe spaces and drop boxes maintained by NGOs. Some obtained condoms from government hospitals or asked their clients to bring them. A few purchased condoms from medical shops, pan shops, and kirana stores. Generally respondents found condom services provided by the NGO accessible and were satisfied with condom services provided by the NGOs.

Conclusions and Recommendations

Stigma, discrimination, and violence dominate the lives of most members of the key populations interviewed, and strongly interfere with creating an enabling environment for HIV prevention. The sources of stigma, discrimination, and violence are many—they include family members, clients, health facilities, the police, the wider community, and in some cases, NGOs. Although NGOs overall are viewed positively as sources of information about HIV and of condoms, there is a great deal of resentment and disillusionment with them because of unfulfilled expectations, often around livelihood assistance.

Overall, social capital among the different respondent groups is low. Participants are distrustful of and feel unsupported by peers, formal institutions, and the community. Many are wary of peer groups, either because they lack cohesiveness, as noted by some men who have sex with men respondents, or because they don't want their identity as a sex workers or as someone who is HIV positive known to anyone outside of their families or NGO staff. There is also a high level of internalized stigma among respondents and this contributes to low self-esteem.

These findings have implications for the development of the FPP as well as wider applicability to other prevention projects focused on key populations. The following recommendations emerged from the study:

Family-level interventions are needed to foster support of key populations.

While family members, including spouses, can be a source of stigma and violence, they can also provide individuals with needed support and assistance. Individuals who reported a supportive family environment were more likely to show signs of self-esteem and self-worth, and to be better equipped to cope with stigma. This underscores the need to examine the extent to which trust and support can be fostered among families of key populations.

Strategies to involve clients of sex workers must be part of the overall program.

Clients of sex workers represent one key, relatively neglected group of people. Not only are they major perpetrators of stigma and violence, but as the majority of them are married and are likely to have multiple sexual partners, they are also a bridge into the general population. Therefore, activities are needed to engage them in building an enabling environment.

Awareness raising and sensitization programs with doctors and other health staff are essential.

Although health services are available through a range of providers (NGO, government, etc.), the quality of the services vary and key populations often suffer stigma and discrimination at the hands of health care providers. This highlights the need to educate and sensitive health care providers to the need for confidential and destigmatizing service delivery.

Peer support groups need to be carefully structured to take into account the challenges and sensitivities of different key populations.

Training in group management and dynamics needs to be made available to established and newly-formed peer support groups. These groups can then, with the assistance of NGOs and other advocates, be in a stronger position to push for legal rights, safe spaces, and better access to public services. Efforts are also needed to help groups maintain confidentiality and to communicate this group norm to prospective members.

NGOs need to increase the involvement of key populations in decision-making and improve their intrapersonal and organizational skills.

Members of the key populations interviewed felt that they had not been consulted enough about NGO programs nor involved actively. Therefore, NGOs need to give them more voice in planning and implementing programs, which could contribute to increased empowerment and feelings of program ownership by key populations. In addition, NGOs need to develop a range of skills related to interpersonal communication, organizational strategic planning, partnership building, advocacy, and resource mobilization, which would contribute to their ability to empower key populations to practice HIV- preventive behaviors.

Efforts to engage people in powerful positions in the fight against stigma are needed.

To mitigate stigma and create an enabling and empowering environment to practice HIV protective behaviors, programs need to focus on people in powerful positions, including those in government, health professionals, the media, the legal profession, and the police. Raising awareness among these groups will not only assist in ending the vicious cycle of stigma, discrimination, and violence, but by these people speaking out, the silence and fear which often surround HIV with devastating consequences is likely to decrease.

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